

#IASONEVOICE

# Living with HIV, now and then

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The first AIDS-related deaths were [reported](#) in the United States on 5 June 1981. Thirty-six years later, there are almost 37 million people living with HIV. Today, seven of these people share their personal stories; they come from around the world and are between the ages of 23 and 73 years. In this #IASONEVOICE series, International AIDS Society (IAS) Members shed light on the diversity of experiences, perspectives and realities of HIV over time-across ages, countries and backgrounds. Here are their stories ....

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## JOYLENE DZORO, 23

Diagnosed with HIV at age 16

Country of residence: Zimbabwe

Occupation: Social worker

### Take us back to when you first learned you were living with HIV. What did it mean back then and what does it mean today?

Realizing that I was HIV positive meant darkness to me. Today, I am dealing with the situation much better and look forward to my future. I feel like there are good things lining up for me.

### Have you ever encountered any HIV-related stigma? Has this changed over the years?

I experienced HIV-related stigma when I disclosed my status to some girls in my second year at university. Afterwards, I overheard them talking about my HIV status behind my back. I felt so ashamed and empty. I regretted sharing it with them. Later on, I learned that some boys in my class knew about it as well. The way they were talking about it was really bad and I wanted to just quit university and go home. I threw myself on my bed and cried. That was my worst experience. During the university break, I went home and told my aunt, who was also living with HIV, about it. I wanted to be home rather than at university, but she comforted me, told me to be confident and to work very hard at school. I later joined FACT-Chiredzi, a home for people living with and affected by HIV. Being around other people living with and affected by HIV made me feel part of this world again. I've gained more confidence in myself, and now self-stigma and stigma from others don't affect me.

### Looking back, what has been the one key lesson that living with HIV has taught you?

HIV is only a virus and it can never stop me pursuing my dreams. I am going to be who I want to be.

### What role does HIV play in your daily life?

I lost two friends who stopped taking their treatment because of the stigma tied to living with HIV. This is what motivated me to stand up against the stigma in my community and become actively involved in the HIV response. The HIV epidemic has influenced me to contribute to disease control, and today, I am an advocate. I'm tired of hearing about new infections among young people.

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## JAIME LUNA, 29

Diagnosed with HIV at age 22

Country of residence: Panama

Occupation: Chemist

### Take us back to when you first learned you were living with HIV. What did it mean back then and what does it mean today?

When I learned that I was HIV positive, it was a shock. I think this is how most people who are diagnosed feel in the beginning. I wanted to quit my job and my university studies because at that time, I didn't know anything about HIV and thought I would die. A few months later, I attended a support group, which helped me to learn everything that I needed to know about my new condition. Today, I have been working for more than five years in the HIV response at the national, regional and global levels. I work towards empowering other people living with HIV to think positively and focus on improving our quality of life.

### Have you ever encountered any HIV-related stigma? Has this changed over the years?

I encountered stigma just one year before I graduated from university. I won a scholarship to study for a master's degree, but they rejected me when they found out that I was HIV positive. I hope that people living with HIV will face less stigma in the coming years. As long as we have to deal with stigma and discrimination on a daily basis, we need to keep fighting.

### Looking back, what has been the one key lesson that living with HIV has taught you?

The key lesson that I learned from living with HIV is that even if we have to face drawbacks and challenging environments, every day we have a new chance to change people's thinking and the world around us. I have a lot of hope, especially when it comes to changing young people's mindsets. To me, changing people's mindsets is the best way to recognize and realize human rights.

### What role does HIV play in your daily life?

HIV plays an important part in my life. I take my medication every day and try to be a good example to my peers because treatment increases our quality of life. As a chemist, I always try to understand and explain to others how the medication works in our body. Every day, I take time to talk with at least one person who needs advice and some good conversation to feel better.



## SIMRAN SHEIKH, 35

Diagnosed with HIV at age 26

Country of residence: India

Occupation: Senior programme officer,  
India HIV/AIDS Alliance

### Take us back to when you first learned you were living with HIV. What did it mean back then and what does it mean today?

"You have AIDS," a counsellor said to me in 2008. The counsellor spoke to me for more than 20 minutes, but I remembered just that one sentence: "You have AIDS." Only one thing came to my mind: everything is finished. I was a sex worker on the streets of Mumbai when I first learned about my HIV status. I had been an "HIV navigator", a peer outreach worker, for almost eight years then. At the time, the traditional sources of income for transgender women in India were to beg, dance, sing and engage in sex work. Luckily, this changed after the Supreme Court officially recognized transgender women in April 2014.

Today, I am working with India HIV/AIDS Alliance as a senior programme officer for sexuality, gender and rights, a position I have held since November 2010.

### Have you ever encountered any HIV-related stigma? Has this changed over the years?

In addition to the stigma of being a person living with HIV, there is a lot of stigma against transgender people. People like me, who are both a transgender person and living with HIV, are facing double discrimination. This is why, to me, every day means stigmatization.

### Looking back, what has been the one key lesson that living with HIV has taught you?

The stigma I encountered has made me a strong advocate who stands up for the rights of my peers and other people living with HIV.

### What role does HIV play in your daily life?

Today, I can proudly say that living with HIV has led me to become a mediator, an activist and an agent of positive change. Living with HIV and being a transgender person has kept me going all these years and I am proud of it.



### ANTON BASENKO, 36

Diagnosed with HIV at age 16

Country of residence: Ukraine

Occupation: Senior programme officer,  
International HIV/AIDS Alliance in Ukraine

### Take us back to when you first learned you were living with HIV. What did it mean back then and what does it mean today?

My entry point to HIV testing was a harm-reduction programme because at that time, I was a drug user living on the streets. In the beginning, hearing that I was HIV positive was like an announcement of my death. Even though the doctor told me there was treatment available, my immediate reaction was to use drugs even more heavily. I thought that I would die anyway and wanted to have some fun in my last few years. Today, after 14 years of knowing my HIV status and 12 years on antiretroviral therapy (ART), the fact that I am HIV positive opened a new life and even a new quality of life to me. All that I do now, all my activities and the fact that I work for international organizations are because of my HIV status.

### Have you ever encountered any HIV-related stigma? Has this changed over the years?

In terms of my friends and my close environment, such as my relatives and parents, I was lucky because they supported me from the beginning. I experienced stigma and discrimination in other fields of my life, though. It was mainly from medical staff in the hospitals and law enforcement officials since at that time, I was still an active drug user living on the streets with frequent contact with police. One time, when I went to a healthcare facility, the medical staff rejected me and told me that this was a place for “normal” people and that people living with HIV and AIDS should go to the AIDS centre. They told me that I was a risky patient, I would infect everybody around me, and they warned me not to sit here, and not to enter there, as they didn’t see me as “normal”.

Over the years, I would say that a lot has changed for the better – at least in Kyiv. There have been specific projects targeting stigma and discrimination among medical staff or in law enforcement bodies, and this process is still running. Nevertheless, despite the progress in Kyiv and larger cities, I want to emphasize that stigma and discrimination are still present in the rural areas and smaller cities of Ukraine.

### Looking back, what has been the one key lesson that living with HIV has taught you?

Living with HIV provides you with another point of view, another understanding of your life and the lives of people around you. That is the key thing for me: responsibility not only for myself, but also for the people around me. For people with a positive reaction, I want to share adequate peer information and share the same understanding with them. For people with a negative reaction, I want to share adequate information with them, explain to them that HIV is just one among many diseases out there, and that people living with HIV have the same rights as everyone else.

## What role does HIV play in your daily life?

HIV plays an important role in my daily life. It defines my activities and is my motivation to work. It helps me to be happy about simple and daily things; things which I did not consider as something special before. But now I understand that even something like seeing the sunrise or breathing in fresh air is a gift.

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### SHAUN MELLORS, 52

Diagnosed with HIV at age 21

**Country of residence:** United Kingdom  
**Occupation:** Director of knowledge and influence,  
International HIV/AIDS Alliance

## Take us back to when you first learned you were living with HIV. What did it mean back then and what does it mean today?

I was a young student enjoying the daily student life. One day, I collapsed, and when the doctor examined me, she noticed that I had swollen glands. She asked whether I had experienced any weight loss and if I was homosexual. My attempts to come out as gay and claim my identity in public were met with: “You have AIDS and about six months left to live!” Back then, I was referred to and treated as an AIDS “victim” and an AIDS “patient”. I was admitted into a ward in complete isolation with biohazard stickers on the door. Two black plastic bags were taped to the wall – one for my dirty linen and one for my used paper plates and cutlery. The volunteer choir sang Christmas carols in the ward and it was hauntingly reassuring and comforting – even though their voices were only allowed to drift in through the closed door of my isolation ward. I was scared. The way in which the world was treating me confirmed that I was bad and what was happening to me was because of who and what I was.

Today, 30 years later, HIV is very much part of my life. I work and live with HIV and what initially felt like a death sentence has become a calling – for justice, inclusion and acceptance!

## Have you ever encountered any HIV-related stigma? Has this changed over the years?

For me, one of the hardest challenges of living with HIV has not been anything to do with the “condition” itself, but rather trying to deal with self-stigma. As a homosexual man, I felt I was now what my family, community and faith had defined as bad, sinful and against the will of God. My punishment, according to many, was an HIV diagnosis. In their eyes, I was “promiscuous”, living a life of sin, a vector of disease. I felt guilty and ashamed. The media fed into this cycle of negativity, using terms such as “HIV victims”, “AIDS sufferers”, “gay disease”, “guilty” versus “innocent” victims. Growing up believing that my homosexuality was wrong left a powerful imprint inside me. It made some part of me an ally of those awful voices who said that my infection with HIV was a deserved judgement upon me. These are the devastating, destructive workings of internal or self-stigma.

## Looking back, what has been the one key lesson that living with HIV has taught you?

There are many lessons that I have been fortunate to learn during my journey with HIV. The resilience of individuals and community through the power of solidarity to bring about change is immense.

## What role does HIV play in your daily life?

HIV has become me. It informed my activism, shaped my career and drove my passion. I have spent most of my career over the past 30 years working in HIV – whether as an activist, programmer or representative of people living with HIV. I do realize that I am very privileged to have access to good health facilities, proper diagnostics and psychosocial support, if I need it. Taking medication has become a morning routine similar to brushing my teeth. I’m fortunate in that I have been on the same regimen for more than 10 years and have been HIV undetectable since starting treatment more than 20 years ago. HIV is a constant companion, mostly silent and cooperative, but still present. I have a virus in me, which has the ability to make me reflect and be grateful.

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## RICKY TREURNICHT, 68

Diagnosed with HIV at age 46

Country of residence: South Africa

Occupation: Candle maker

### Take us back to when you first learned you were living with HIV. What did it mean back then and what does it mean today?

It meant terror, panic, fear, anger, loss and great sadness. I raged and cried and prepared to die. I felt that I had become an outcast, an untouchable, and was never going to be part of society anymore. I felt the fear of dying, of how I was going to die, waiting for it to happen, of losing friends. I felt ashamed and my whole personality changed. Since the first doctor I went to told me she could not do anything for me, I started taking every kind of pill I could find and went to dozens of healers, but not one actually helped. I lost my business, retreated to a small town, lost interest in everything, and gave away all my precious things.

But as time went on, I began talking about my diagnosis, and after about three or four months, I found a doctor who was an absolute angel. It was when I was very ill that my doctor referred me to a clinical trial, and that was my new beginning.

### Have you ever encountered any HIV-related stigma? Has this changed over the years?

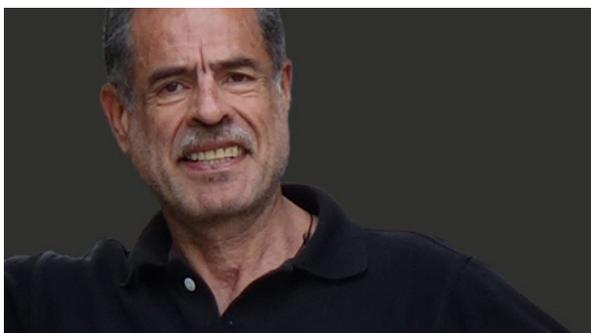
To my surprise, my friends did not desert me. In fact, I made many new and wonderful friends. I met people from all walks of life, all trying to help and give love and advice. A good friend asked me to speak to the children in his school one day and because of that, I found myself again and started speaking to the world. I was probably the first person who spoke publicly about their HIV status in my area, and then I spent years doing it: newspaper interviews, documentaries, articles in magazines, speeches to schools and big companies. By the time I arrived in my small town, everyone there already knew me and, to my surprise, there were no negative attitudes or judgements towards me, as far as I know. Of course there has been discrimination, and I have been aware of it, but there is nothing that someone can say that hurts me anymore.

### Looking back, what has been the one key lesson that living with HIV has taught you?

I have been living with HIV for 22 years, and it has changed my life in many ways. I think it has made me more compassionate and kinder, it has given me greater awareness, and I really love who I am now. I live my life as if every day is my last.

### What role does HIV play in your daily life?

I have a lot of pain in my body most of the time, caused by peripheral neuropathy, arthritis, sore legs, headaches and other symptoms. But I work seven days a week and have to keep myself alive and afloat, and so try to ignore the pains. I am just focusing on staying alive, living for the moment and doing the best I can.



## HUMBERTO ARANGO, 76

Diagnosed with HIV at age 42

Country of residence: United States

Occupation: Activist

### Take us back to when you first learned you were living with HIV. What did it mean back then and what does it mean today?

When I first learned I was HIV positive in 1986, the situation was different from now. There was still a lack of reliable information about HIV, there were few medicines available, and people were dying, practically daily. The doctor who told me I was HIV positive didn't provide any counselling. In the US, stigma was far more rampant than today, and resources of all types were less available. In New York, however, the gay community was active, and at least two institutions were advocating for funds and research, and providing counselling and referrals for azidothymidine (AZT).

I think the situation is far better today. There is a better understanding of the virus and many governments provide information and medicine. People with appropriate treatment can live normal lives. I am aware the situation is not the same everywhere, and even in the countries that show lower rates of transmission, there is a dire situation for many underserved groups. I wouldn't say the fight is over, but we have advanced significantly.

**Have you ever encountered any HIV-related stigma? Has this changed over the years?**

I have not directly encountered external stigma, but self-stigma was instrumental in stopping me from disclosing my HIV status for many years. I think it is important to realize that even if I never experienced direct discrimination, the community and culture play such an important role in shaping perceptions, including self-perception.

It was mainly while travelling in other countries that I learned about the terrible effects of stigma suffered by some people. Individuals being fired from their jobs, gay individuals facing double discrimination, jokes, name-calling, and many other forms of discrimination – which obviously affected me too. I believe things have improved substantially in areas of the world with which I am familiar. Activism, information and familiarity with people living with HIV have played major roles in improving the situation.

**Looking back, what has been the one key lesson that living with HIV has taught you?**

If I have to select one lesson, it is the fact that stigma and discrimination impede empowerment and the ability to make appropriate decisions. We need to understand the role and effect of stigma and discrimination and work to defeat them. Greater understanding is necessary. We should take courage from the achievements of individuals and organizations that have been able to change societal values and force a society into providing assistance.

**What role does HIV play in your daily life?**

It is undisputable that HIV changed my life significantly. I have gone through much fear and pain and still grieve for so many friends, colleagues and valuable individuals that I have lost. But a lot of the fear has subsided and I live a regular life. My levels of awareness and consciousness are much higher today, and I am much more conscious of my own worth and the worth of others. My viral load is undetectable and I work actively to keep it that way. It is perhaps paradoxical, but HIV matters a lot today and yet it doesn't. It does not play a very important role in my life but it does.

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